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A B O U T U S

Parkinson's Post is published by the Northwest Parkinson's Foundation, a 501(c)(3) charitable organization.

Our mission is to establish optimal quality of life for the Northwest Parkinson's community.

We welcome comments and inquiries regarding this newsletter and all our activities. Our contact information can be found on the last page of this newsletter. We look forward to hearing from you!



NORTHWEST
PARKINSON'S
FOUNDATION

Upbeat family finds all is not lost in loss

By Shannon Carr-Cohen

It was July 9, and I was slowly but steadily pedaling from Winlock to Vader, WA. Anxiously anticipating a shower and my sleeping bag, I looked up and asked Mom for another push to get me through the last five miles of the first day of my third Group Health Seattle-to-Portland Bicycle Classic as a member of Team Parkinson's.

This year was different from the others. In the past I'd ridden with the excitement of knowing I could share my accomplishment the next Monday with Mom. But during this year's 204-mile trek, I was constantly reminded I was now riding in her memory, in hopes no one will suffer the way she did ever again.

Parkinson's disease dementia is the worst thing that happened to my mother and our family. But today, we feel blessed. Janie Carr's battle ended this May, one day before her 62nd birthday—a peaceful end to an excruciating journey.

Mom's struggle with Parkinson's began long before her diagnosis in the fall of 1994. Her father had been diagnosed with Alzheimer's in the late '70s and died of pneumonia in 1984. On his death, research of his brain found he'd never had Alzheimer's. He'd actually suffered from Parkinson's dementia. With her own Parkinson's diagnosis, my mother's life was again profoundly changed.



Shannon Carr-Cohen, left, and Susan Carr are all smiles in Portland, OR, at the finish of the Group Health Seattle-to-Portland Bicycle Classic on July 10. The sisters rode in memory of their mother.

While it might be tempting to feel sorry for Janie and her family, she'd never have wanted anyone's sympathy. And as a family, we have adopted her positive way of thinking. We hold fast to the knowledge that, despite this disease and Mom's struggles, all is not lost.

Janie Carr was a proud wife and mother of four who had only known one speed—*fast!* Janie married her college sweetheart right after graduation and they were off and running to start a family.

No one could have asked for a better mom. Being a mother seemed to be her calling. Janie and Jerry raised four very different daughters, acknowledging and adoring each for those differences.

Raised by an FBI agent and a teacher for the deaf, Janie and her siblings were taught to take every day as an opportunity to give thanks and to help others.

Janie took that to heart, managing to keep her family first, while volunteering

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Tackling changes in mental functioning with Parkinson's

By **Martha Glisky, Ph.D.**
and **Brenda Havellana**

Often hidden behind the more obvious physical symptoms of Parkinson's disease are the lurking cognitive changes associated with this illness. By some estimates, up to 20 percent of people with Parkinson's will develop an actual dementia, but milder cognitive impairments are a distinct and common feature of this disease that can have a significant impact on quality of life.

Parkinson's can affect several areas of cognitive functioning. One is a cluster of abilities known as "executive functions." Examples of executive functions include performing multiple tasks simultaneously, planning, sequencing, organizing, problem solving, and abstract reasoning. Inhibiting, stopping, and switching behaviors are also aspects of executive functioning. Some people experience difficulties in all areas, while some have selective deficits.

As the name implies, executive functions are typically high-level abilities that oversee many other cognitive abilities. As a result, difficulties in executive functioning can secondarily impact other abilities, such as memory.

Executive functioning is essential for a broad range of abilities necessary for working through the daily challenges of life. Thus, when these abilities are compromised, as is the case with many Parkinson's patients, there can be challenges to the tasks of daily living. For example, patients who are less efficient at multi-tasking might report increased difficulty preparing family meals, given that numerous steps must be completed simultaneously and in a timely manner during meal preparation.

Others find driving becomes increasingly overwhelming, as it necessitates paying attention to passengers, road signs, traffic lights, and other drivers.

Executive dysfunction can also hinder an individual's abilities in planning and structuring. Patients experiencing such problems might report greater difficulty setting and attaining goals. For instance, one patient with Parkinson's reported that although he knew he had several tasks to accomplish each day, he felt like he spent his time "walking in circles" and ultimately making minimal progress on his to-do list.

Some Parkinson's patients find they are less efficient at managing personal finances. For instance, individuals who once prided themselves on their mathematical mastery have reported that balancing their checkbooks has become an arduous task no longer accomplished with the ease they were once accustomed to.

Some patients may find they have difficulty inhibiting or controlling their emotions or behaviors. They may say inappropriate things, have trouble managing emotional responses, or find it difficult to engage in or disengage from certain activities.

Adjusting to the changes

Despite the challenges presented by Parkinson's and the related executive dysfunction some people experience, there are ways to compensate for these difficulties. Some helpful tips include:

- ◆ Beware of biting off more than you can chew. Taking on too much at a time can result in feeling overwhelmed, frustrated and exhausted.

- ◆ Try to engage in one activity at a time. Avoid multi-tasking or switching back and forth between tasks.

- ◆ When it comes to meal preparation, instead of preparing a meal alone cook with a friend or family member. By distributing the work, one will be less likely to feel overwhelmed by the

multi-tasking demands of meal preparation. In addition, one might reap the many benefits of good company!

- ◆ When it comes to driving, build extra time into your schedule for the commute. Giving yourself a cushion of time can decrease the stress associated with arriving at your destination on time, and can give you additional decision-making time when you're faced with a confusing traffic situation. Don't try to do anything else while driving. You need to reduce your distractions and focus only on the important task of driving. Turn off the radio, limit conversation, and keep your thoughts on the task at hand.

- ◆ Alternatively, allow yourself to be chauffeured. Occasionally handing off the car keys and savoring the opportunity to view the passing scenery is a nice break from the demands of driving. Plus, you might find yourself delighted by the companionship of your escort for the day.

- ◆ When it comes to balancing your checkbook, ask a friend or family member to check your math. If privacy is a concern, your financial institution may be able to assist with bookkeeping or suggest a private contractor.

- ◆ Use external aids to help with planning and organizing. Write things down then organize or sequence the information from your written copy.

- ◆ Stay organized. Have specific places for specific things and always return them to that spot.

- ◆ Use a day planner. Write down your daily schedule ahead of time so that you can plan your day in advance.

- ◆ Finally, keep in mind that you are only one person with natural human limitations. Take your time and don't be afraid to ask for help.

Martha Glisky is a neuropsychologist at the Booth Gardner Parkinson's Care Center in Kirkland, WA, and Brenda Havellana is a doctoral student at Seattle Pacific University as well as a practicum student at the Center.

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for many organizations and impacting countless lives. Her philanthropy included raising money to help send kids to Catholic school and sponsoring a young South American



Photo courtesy of Shannon Carr-Cohen

Janie Carr shares a happy moment with her oldest granddaughter, Amanda Jane, in September of 2002.

boy's education. She also gave her time, teaching adults to read and instructing children in the Catholic faith.

She would be considered an expert in time management in the high-stress, busy lifestyle many of us

lead these days. And she managed it all while having fun. Playing tennis—well, I might add—kept her fit. Business ventures kept her creative mind busy. And family and friends always gave her reason to throw great parties.

All of that changed once she couldn't serve overhead or get to those high lobbs on the tennis court. A misdiagnosis of a "frozen shoulder" and worthless physical therapy kept her returning to the doctor with more questions.

By the time she was struggling to sign her name to a check at the grocery store, we were all wondering what could possibly be wrong. I was there the day she received the news. Neither of us could believe it. Mom was only 51—how could this be happening?

The doubt persisted, delaying her treatment as we all searched for the "right" answer, because this couldn't possibly be it. Mom and Dad got second and third opinions, looking for anything else. Eventually a Parkinson's specialist made it very clear what the situation was, prescribing a medication to help.

A couple more years passed. Mom was slowing down but still exercising and running her business the best she could. But things got worse. Mom not only walked slower than we could imagine but she'd stopped writing all together. She also started to forget and misplace things and hallucinate.

She hadn't sent the family Christmas letter in years, and when people asked we'd say things like, "She's okay" or "She had a good day yesterday."

As our definition of good and bad days changed, so did Mom's diagnosis. Now she had dementia, and at just 55. We knew that one day she might not know who we were.

Mom's care was a regular concern. It was hard to know what she needed because every day posed a different chal-

lenge and each stage of the disease made the last seem so much easier. When Mom fell twice in three months, the second time breaking her hip, there was no longer a choice: Our 58-year-old mother needed the constant care of a nursing home.

Mom enjoyed the activities offered at the nursing home, the opportunity to attend Mass, and the chance to see her husband, kids and grandkids regularly. But each meeting with the doctors and nurses was worse than the last, until the day the staff called us in to tell us Mom had five to seven days to live.

So why do we feel blessed? That's an easy one.

In the 13 years of this illness, my parents celebrated their 40th wedding anniversary. They saw all their daughters graduate from college. They also saw us all marry men they welcomed into our family. Janie had the opportunity to meet her three beautiful granddaughters, too. When Mom was healthy, we all knew she'd make a wonderful grandma someday. Fortunately, she got that chance—and she loved it.

These milestones and others along the way provide wonderful memories. They also illustrate that a family that stays together through tears and pain will also laugh and celebrate together.

Shannon Carr-Cohen lives in Milton, WA, with her husband, Dave, and their daughters, Amanda and Caylee. She recently became a high school teacher, following her mother's path of helping others. She and her family are committed supporters of the Northwest Parkinson's Foundation—donors, volunteers and champions of the cause.

Team Parkinson's seeks runners

Team Parkinson's 2005 is working toward its \$150,000 fund-raising goal—and you can help.

If you're a runner, consider joining us! We're building our first-ever group of runners (and walkers) to take part in the HarrisDirect Seattle Marathon and half-marathon on Nov. 27. (Team members may also choose their own event.)

Team members who raise money earn team shirts, a goody bag and a chance for prizes. As they train, they invite friends, family, coworkers and neighbors to sponsor their effort with donations that support the cause—quality of life for the Parkinson's community. To learn more, visit www.nwpf.org, email joanna@nwpf.org or call 1.877.980.7500.

Not a runner but still want to help? Consider a contribution in honor of Team Parkinson's today. Use the enclosed envelope to make your tax-deductible donation.

To date, Team Parkinson's cyclists have raised nearly \$90,000. Thank you, team!!!

Simple strategies aid in recall

By Doug Mason, Psy.D., L.C.S.W.

Memory is a two-step process. The first step is to put something into the memory and the second step is to get something out. Although we notice memory lapses as we try to retrieve information, it is the retention—or getting the information in—that we have the most control over.

Try new strategies for getting information into your memory. Here are some ways to get the data in:

- ◆ *Categorize it.* Placing information into categories makes it easier to remember. For example, organize your grocery list items into categories. Lunch meat and hamburger can be placed into the category of meat. Eggs and milk can be placed into the category of dairy. Doughnuts and candy can be placed into the category of treats. We now only need to remember three categories rather than six separate items.

- ◆ *Chunk it.* Chunking involves learning small portions of a concept and later putting them together to form the whole. Phone numbers are a good illustration of this: It's easier to remember two small sets of numbers than one seven-digit number. If you're trying to remember an article, start with the main premise. Associate related themes back to the main premise. By breaking down the information, you're actually checking the accuracy of the information and thus enhancing your memory.

- ◆ *Sense it.* By employing all the senses, you're using different portions of your brain to aid in memory. Your sense of smell is much deeper in the brain than vision. Visualizing the brightness of an object uses different cells from imagining the color of it. Imagine yourself in the grocery store collecting items within the three categories defined above. Visualize the items being put into the cart. See the colors, verbalize the items, feel the textures and smell the scents associated with the

food groups. Actively use all your senses to aid in the details of memory.

- ◆ *Attach it.* It's easier to remember things if they carry some significant meaning. Try to decide why what you want to remember is important. Perhaps the above grocery items are part of a special dinner you're preparing for a friend. Attach the food items to the dinner and the emotion associated with that evening.

- ◆ *Use humor.* Compose a humorous phrase, song or mental image to assist in remembering. When humor is attached to the item to be remembered, it is both entertaining and more easily recalled. And humor will help you relax, stay positive and feel less burdened with stress and tension. Creativity goes a long way toward remembering.

- ◆ *Label memory files.* By consciously choosing key word connections within your mind in order to place memories, you are saving space in your mind and enhancing access by creating an anchor by which to later navigate back to that memory. You can also link your visualization, auditory memory and other sensory perceptions to this label to aid in memory improvement. Labeling memory files allows you to link one word with whole concepts.

- ◆ *Be creative and flexible.* Ask yourself a simple question: "What is another way I can look at this problem?" Rigid thinking is often a precursor to poor memory. Examine the problem at hand. Turn it over and look at it from all angles. Put it down and do the same later. Quality memory associations are formed by examining things from different perspectives. Flexibility will give more paths to recall.

Doug Mason is a neuropsychologist in private practice at The Memory Doctor LLC in Clermont, FL, and author of the book, The Memory Doctor. Other publications include The Memory Workbook and The Mild Traumatic Brain Injury Workbook.

RESOURCES YOU CAN USE

DVD serves straight talk

A new educational DVD, "Managing Parkinson's: Straight Talk and Honest Hope," is being offered free of charge. The brainchild of patient Mike Shanahan, the DVD gives clear information to the newly diagnosed as well as those who live in communities with few Parkinson's resources.

The DVD covers Parkinson's and its treatments, living better with the disease, and patient stories. Neurologists, neuropsychologists, psychiatrists, physical therapists, nutritionists and other health professionals helped script and narrate the DVD.

Supplied by the Washington state chapter of the American Parkinson's Disease Association, the first 25,000 DVDs will be given away. To request a copy, contact the Northwest Parkinson's Foundation at 1.877.980.7500 or info@nwpf.org.

Save the date!

The Washington state chapter of the American Parkinson's Disease Association will host its 21st Annual Parkinson's Symposium on Oct. 8 at the Shoreline Conference Center in Shoreline, WA. The day of presentations will offer the latest medical information, patient resources and networking opportunities. Dr. A. Jon Stoessl, Director of the Pacific Parkinson's Research Centre at the University of British Columbia, will give the keynote talk on Parkinson's progression and neuroprotection.

To learn more, call 206.543.5369 or visit www.waparkinsons.org.

New medications offer advances in treatment

By Travis Sonnett, PharmD

As medical technology advances, new modes of therapy are being unveiled that were previously unavailable. Parkinson's is a disease for which new therapies that show promise in relieving symptoms are always welcomed.

Spheramine® is one such therapy, using new medical approaches to treat the motor symptoms of Parkinson's disease. This cell-based therapy sets out to treat the dopamine depletion that occurs with Parkinson's disease. Spheramine® uses human retinal pigment epithelial (hRPE) cells found in the eye to replace dopamine-producing cells in the damaged portions of the brain.

The retinal cells naturally produce levodopa as well as dopamine and express dopamine receptors. Scientists have cultured this cell type from donated eyes, producing enough cells to treat potentially thousands of individuals.

Previous studies have shown that implanting the hRPE cells directly into the brain has beneficial effects, but that the cells do not survive long enough to promote a substantial decrease in motor symptoms. This is because the body defenses of the host destroy the cells as they would a foreign substance, thus eliminating any benefit that would occur.

Immunosuppressive therapy could be used concurrently, but the side effects, cost and duration of benefit from the cell implantation remain limiting. Thus, the use of a carrier was developed to enhance the benefit of the hRPE. This technology, known as cell coated microcarrier (CCM™), increases cell survival substantially and is harmless to the individual. The microcarrier is made of gelatin, which provides a surface for the cells to anchor on. Combining hRPE with CCM™ results in the production of Spheramine®, an implantable therapy that does not require immunosuppression.

Animal studies have yielded good results and tolerability to Spheramine®. Both rat and primate studies yielded significant improvements in Parkinson's symptoms. A clear increase in dopamine uptake was also shown in studies involving primates transplanted with Spheramine®.

After evaluation of the safety and efficacy data in animal studies, a small study involving six Stage III to Stage IV Parkinson's patients was begun to evaluate the safety and effectiveness of Spheramine® in humans. Each patient underwent implantation surgery and was followed with periodic monitoring of improvement, side effects, blood chemistry and related tests to assure the therapy was not causing undue harm.

Six patients underwent follow-up evaluations through nine months, and three patients continued evaluations through

12 months. Improvements of the Unified Parkinson's Disease Rating Scale (UPDRS) and the Timed Motor Tests continued through the evaluations, with a mean improvement at 9 months of 43 percent. A significant 37 to 53 percent reduction in duration of the patient "off" state was seen in half the patients, while three displayed a lower dyskinesia rating score than their baseline value.

The research is continuing in a 68-patient FDA Phase IIb trial to further investigate the effectiveness and safety of this therapy. The study is expected to conclude mid-2006.

While Spheramine® is still under investigation, it offers a bold approach to the treatment of Parkinson's disease through ideas spirited both in cell replacement and implantation technology.

Travis Sonnett is a geriatric pharmacy resident at Washington State University's College of Pharmacy in Pullman, WA.

Rasagiline due for fall release

By Travis Sonnett, PharmD

Several new medications being released in the near future are showing promise in treating Parkinson's disease. One new agent expected to be released this fall is rasagiline (Agilect®), a novel agent with an exciting mechanism of action that offers more options in the treatment of Parkinson's.

Rasagiline is a monoamine-oxidase type B (MAO-B) inhibitor that binds the enzyme irreversibly. Inhibition of MAO-B prevents the breakdown of dopamine and phenethylamine (PEA) and the production of hydrogen peroxide.

Rasagiline has been studied in three large trials. While still not completely understood, the drug has been shown to treat Parkinson's symptoms at all stages of the disease and—unlike its predecessor, selegiline—offer some neuroprotection. In animal studies, rasagiline yielded increases in surviving neurons in the substantia nigra and prevented neuron death by free radicals.

Rasagiline has been well tolerated in human trials, with the most common adverse effects being headache, infection and dyskinesia. Other side effects included dizziness, arthralgia, nausea, back pain, general pain, asthenia, and accidental injury, all of which occurred in fewer than 10 percent of patients. No significant changes in blood pressure were noted.

HELPING PAGES

The Northwest Parkinson's Foundation would not exist without your support. Donations sustain programs and services that help Parkinson's people live better. If Parkinson's has touched you or someone you care for, please consider supporting our work through a gift. Those listed here gave between June 10 and August 18, 2005. Thank you, friends!

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New board members start their service

The Northwest Parkinson's Foundation extends a warm welcome to three new board members.

Bill Benfield is a Parkinson's patient and a pharmacist with a Ph.D. in hospital administration. **Bill Johanson, M.A.**, whose father has Parkinson's disease, is a neuroscience specialist with Novartis.

Mitch Weinberg is vice president for Medical Affairs at Evergreen Healthcare. He holds both an M.D. and Ph.D. He replaces Louis Filhour on the Northwest Parkinson's Foundation board. Filhour recently left his post as vice president for Patient Services at Evergreen for a position outside the region.

THE CENTER

The Booth Gardner Parkinson's Care Center is a regional center of excellence in the treatment of Parkinson's patients. The Center offers patient assessments and ongoing care. The staff—neurologists and neuropsychologists; physical, occupational and speech-and-swallowing therapists; and others who specialize in caring for Parkinson's people—work as a team toward each patient's improved quality of life.

**BOOTH GARDNER PARKINSON'S
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